i was a clown in a workled that was not a circus. learning to type has been my rebirti as a nosrmal person. people understand that i am an intelligent person. e very one wants to be treated with respect. I AMN NOT A UTISTIVC OH THJE TYP I CAN TRY TO TYPE UNTIL YOU TAKE AWAY MY LOVE. I RALLY NEED THE TYPEWRITER. i really like to type because i am very good spieaking that way. i only talk with my voice on occsion because w it doesn't work right. i get angry because of this. i want you to know i am very smart and only can't talk. WORLDZZ LIKEMEJINE NEEECD VOTO BB EI YYLLOXPLOREEDH I Y YELL INSIEEDEMYSEELF TO BEEEAAUTISTIC IIIT IS DAEMSIE LIKKE BEIENG IN SI DE A mosinmacHINE THANK YOU FOR TALKING TO ME LIKE I UNDERSTAND. I LIKE YOU. DO YOU THINK THAT I WILL

Communication UNBOUND

How Facilitated Communication Is Challenging Traditional Views of Autism and Ability/Disability

Douglas Biklen

Kitchener Public Library thanks
Waterloo Wellington Autism Services
for the donation of this material.

COMMUNICATION UNBOUND

How Facilitated Communication Is Challenging Traditional Views of Autism and Ability/Disability

Douglas Biklen

TEACHERS COLLEGE PRESS

Teachers College, Columbia University
New York and London

Published by Teachers College Press, 1234 Amsterdam Avenue, New York, New York

Copyright © 1993 by Teachers College, Columbia University

All Rights reserved. No part of this publicaton may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopy, or any information storage and retrieval system, without permission from the publisher.

The following chapters have been adapted and expanded, with permission, from previously published material:

Chapter 1: Biklen, Douglas, "Communication Unbound: Autism and Praxis," *Harvard Educational Review,* 60:4, pp. 291–314. Copyright © 1990 by the President and Fellows of Harvard College. All rights reserved.

Chapter 2: From "New Words: The Communication of Students with Autism" by D. P. Biklen and A. Schubert, 1991, *Remedial and Special Education, 12*(6), 46–57. Copyright © 1991 by PRO-ED, Inc. Reprinted by permission.

Chapter 3: "I AMN NOT A UTISTIVC ON THJE TYP' (I'm not autistic on the typewriter)." (1991). *Disability, Handicap & Society, 6*(3), 161–180.

Chapter 6: "Facilitated Communication: Implications for Individuals with Autism" in *Topics in Language Disorders,* Vol. 12, No. 4, with permission of Aspen Publishers, Inc., © 1992.

Library of Congress Cataloging-in-Publication Data

Biklen, Douglas

Communication unbound: how facilitated communication is challenging traditional views of autism and ability-disability / Douglas Biklen

p. cm. — (Special education series ; #13)

Includes bibliographical references (p.) and index.

ISBN 0-8077-3222-2 (alk. paper). — ISBN 0-8077-3221-4 (pbk.: alk. paper)

1. Facilitated communication. 2. Autism—Patients—Language. 3. Autism—Patients—Rehabilitation. 4. Mentally handicapped—Language. 5. Mentally handicapped—Rehabilitation I. Title.

II. Series: Special education series (New York, N.Y.) ; #13.

RC429.B55 1993

616.89'8206516—dc20 92-34555

Printed on acid-free paper

Manufactured in the United States of America

99 98 97 96 95 94 93 7 6 5 4 3 2

Contents

Introduction xi

1 Facilitated Communication 1

Toward Understanding Facilitated Communication: A Qualitative, Hypothesis-Generating Approach 3
Origins of Crossley's Discovery 5
Observations of First Assessments 7
Doubts: Facilitation or Manipulation? 10
Behavior and the Person 13
Autism As We Have Understood It 15
An Alternative Interpretation of Unusual Communication 17
Principles of Facilitated Communication 21
Conversational Communication: A Maintenance Session 21
The Question of Proof 27
Conclusion 28
Notes 30

PART I USING FACILITATED COMMUNICATION 33

2 The Syracuse Experiment: Getting Started with Facilitated Communication 35

One of Our First Students 37
Observing Students Using Facilitated Communication 40
Facilitated Communication: With Whom Should We Try It? 41
Getting Started 48
Facilitating with George 50
The Students' Words 53
Where Did the Students Learn to Read and Do Math? 57
Conclusion: Recurring Questions 59

3 I AMN NOT A UTISTIVC OH THJE TYP [I am not autistic on the typewriter] 62

Echoes 62
Students Who Speak in Echoes 66
Students Who Type Echoes 70
Overcoming Persistent, Forceful Echoes 72
Generalizing Communication to Additional Facilitators 74
Independence/Interdependence 76
When Echoes Reintrude 77
Apraxia and Voluntariness 79

PART II THE DIFFICULTIES OF CHANGE 85

4 Many Breakthroughs 87

One Thing Leads to Another 87
Writing Versus Talking 91
Who Will Believe? 94
Facilitated Handwriting 96
Communicating Through Lyrics 98
How Many Breakthroughs Must There Be? 100
Breakthrough in Denmark 102
Conclusion 107

5 The Validation Controversy Returns: Are the Words Theirs? 110

Negative Positivists 110
A Father's Letter 116
Testing 124
Unobtrusive Validation 127
Conclusion: Cautionary Notes 131
Notes 136

PART III RETHINKING DISABILITY 137

6 Typing to Talk, Typing to Dream 139

Introduction 139
Changing Perspectives: Selves, Parents, Teachers, Friends, Others 140
Schoolwork and the Communication Context 148
Conversational Communication with Peers 153
Typing to Communicate: Self-Determination 156
Feelings 158

Not a Cure for Autism: Behavior Persists 163
Conclusions: Making the Conditions Right 170
Notes 171

7 Ending the Ability/Disability Dichotomy 173

Learning About the Ability/Disability Dichotomy 173
Forced to Abandon the Blinders of "Disability" 174
What Is Required in Order to See the Person? 178
Why Is It so Hard to Believe the Communication of People Presumed Retarded? 182
The Meanings of Facilitated Communication 184
Notes 189

Appendix: "How-To" Training Materials 191
References 207
Index 213
About the Author 224